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# **Development of a pathway to facilitate gastrostomy insertion for patients with MND**

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## **Abstract**

A pathway has been developed using a multidisciplinary group from within specialist palliative care to ensure a comprehensive approach to the insertion of gastrostomy tubes for patients with motor neurone disease (MND) with swallowing difficulties. The pathway has ensured that there is a coordinated approach and the professionals involved are clear as to their responsibilities in the discussion and planning of the insertion, ensuring the best support for the patient and family.

## **Key words**

Gastrostomy   Motor neurone disease   Palliative care

MND is a progressive neurological disease with no cure, and the best that can be offered patients is a treatment that may slow the rate of progression (Anderson et al, 2005). There is progressive loss of nerves, leading to muscle weakness and this may be manifested as weakness of arms and/or legs, breathing difficulties if the respiratory muscles become affected or problems with speech and swallowing if the muscles of the head and neck are affected (Wagner-Sonntag and Prosiegel, 2006).

Swallowing difficulties are very common in MND. Twenty-five per cent of patients present with problems of speech or swallowing – this is often referred to as pseudobulbar palsy (Leigh et al, 2003). The majority of all patients develop the same problems as the disease progresses, although this is different for every individual. During the progression of the disease, 90% will have swallowing problems (Oliver, 1996) and many will need to consider alternative methods of feeding (Heffernan et al, 2004; Rio et al 2005).

### Assessment of swallowing and nutrition

As a person with MND deteriorates, swallowing may become difficult. This may present itself as a direct complaint but may also be less obvious – as the person loses weight or takes longer to eat meals. The careful observation and discussion about meals and swallowing may be necessary to allow the patient to realise that there is a developing problem. The involvement of the speech and language therapist and dietitian is important so that they can make a full assessment (Wagner-Sonntag and Prosiegel, 2006).

Investigations may be necessary, such as a videofluoroscopy, although with a careful and full clinical assessment this is rarely needed. However, if there is suspicion of aspiration of food the video may show the extent and the problems that will be encountered.

### Augmentative feeding in MND

If swallowing is deteriorating there is a need to consider the following ways of helping the patient and family:

- Careful positioning – ensuring that the patient can swallow as effectively as possible
- Modification of the consistency of the food – often custard consistency is easier to swallow and thickening agents, such as Thick and Easy – can be added to liquids to ease swallowing
- Careful feeding techniques are essential so that the correct amount of food is presented in the most appropriate way for the patient to swallow. Families and carers may need careful instruction in feeding techniques
- Food must be presented well and kept hot so that it can be enjoyed fully, as this will improve the appetite and the amount of food taken
- The insertion of a feeding gastrostomy.

### Gastrostomy feeding

The insertion of a gastrostomy may be undertaken in two different ways

- A percutaneous endoscopic gastrostomy (PEG) – when the patient is sedated and an endoscope is passed into the stomach allowing the gastrostomy tube to be inserted through the abdominal wall and pulled through by the endoscope. The procedure requires some sedation but takes only a few minutes
- A percutaneous radiological gastrostomy (PRG) – when a naso-gastric tube is passed into the stomach and the stomach identified using radio-opaque dye and the tube is inserted while monitored by

the radiologist. This does not require sedation and the patient can even receive non-invasive ventilation if necessary during the procedure.

The insertion of a gastrostomy can be seen by patients as a major intervention. If a PEG is considered this needs to be inserted earlier, as the patient needs to have good respiratory function. Evidence-based guidance suggests that if the FVC is less than 50% of normal there is increased morbidity and mortality (Miller et al, 1999), and some sources suggest that the FVC should be over 60% or 70% of normal. This is less of an issue if a PRG is being considered.

The discussion about augmentative feeding needs to be earlier in the disease progression, rather than only when there are severe swallowing problems. The discussion is part of a process and may be introduced over a period of time – initial discussion about swallowing problems and weight loss, consideration of alternative feeding systems, demonstration of a gastrostomy, meeting patients with a PEG or PRG, and then a chance to discuss the options (Miller et al, 1999; Rio et al 2005).

### Development of the gastrostomy pathway

In the Medway and Swale area, the MND clinical team is involved in the care of up to 20–25 patients with MND at any one time; this is the expected number for the population of the area, which is 360 000. MND has a prevalence of 7/100 000. Patients and families are discussed on a monthly basis by the team, with their permission, and they are seen regularly by different members of the team – the consultant in palliative medicine, dietitian, home care nurse, speech and language therapist, physiotherapist, occupational therapist, social worker, MND Association Regional Care and Development Officer and local visitor. Any member of the team may discuss the issues of nutrition, but usually the speech and language therapist and dietitian would lead on these issues.

It was apparent to the team that following the discussion, the organisation and planning for the insertion was often haphazard and unplanned. The patients would need to be referred to the gastroenterologist, who would undertake the procedure and would usually be admitted to the Wisdom Hospice prior to the procedure and for a few days afterwards, when the patient and family could discuss the gastrostomy and learn how to use it. On the return home the local district nurse would be involved in the care of the PEG or PRG site and coordinate the feeding regime, in collaboration with the dietitian. The feeds would need to be prescribed and ordered and there was the need to have the correct equipment at home.

Following an incident when a patient returned home from hospital with a PRG, and there was no equipment to allow the feeding regime to be started, the team felt it important to develop a pathway and guidance to ensure the procedure was planned and clear. A group from the MND clinical team decided to look at the production of a pathway and involved the wife of a patient who had died from MND and the nurse from the company that provided the feeds.

The group met on ten occasions and involved other members of the MND clinical team as necessary, as well as specialists from the regional MND Care Centre at King's College Hospital, and over a period of several months the pathway was produced. The pathway includes:

- Decision-making for a PEG or PRG
- Organisation for the admission to hospital (for PRG) or hospice (for PEG)
- Communication with all health and social care professionals involved
- Ensuring arrangements for admission, blood test and equipment are all in place
- Clear pathway for admission and transfer to the local hospital for the procedure
- Initial care of the gastrostomy
- Training of patient and family in the care and use of the gastrostomy
- Training of the community services in the care and use of the gastrostomy
- Clear indications of the professional responsibility for the tasks defined in the pathway.

The pathway is shown in *Figure 1*. There is also a proforma listing the actions that are needed throughout the pathway so these can be checked off as the patient moves along the pathway, and no action is missed. This can also be used to audit the use of the pathway.

## Audit of the pathway

Over the past two years, four patients have required the insertion of a gastrostomy. The pathway has been used on all of these occasions and the care and coordination has improved. The patient, family and all staff involved in the care of the patient are more aware of the procedure, and there have been no delays or problems in the provision of equipment or feeds. The patients and families have been grateful for the use of the pathway and the health and social care professionals have all been appreciative of the coordinated approach.

## Conclusion

As the result of an issue raised in the care of a person with MND, a pathway has been developed involving a multidisciplinary and multi-agency group, including a family member. In this way, the care has been improved and the pathway can continue to be modified as the procedures develop.

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# Percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG) pathway for people with motor neurone disease (MND)

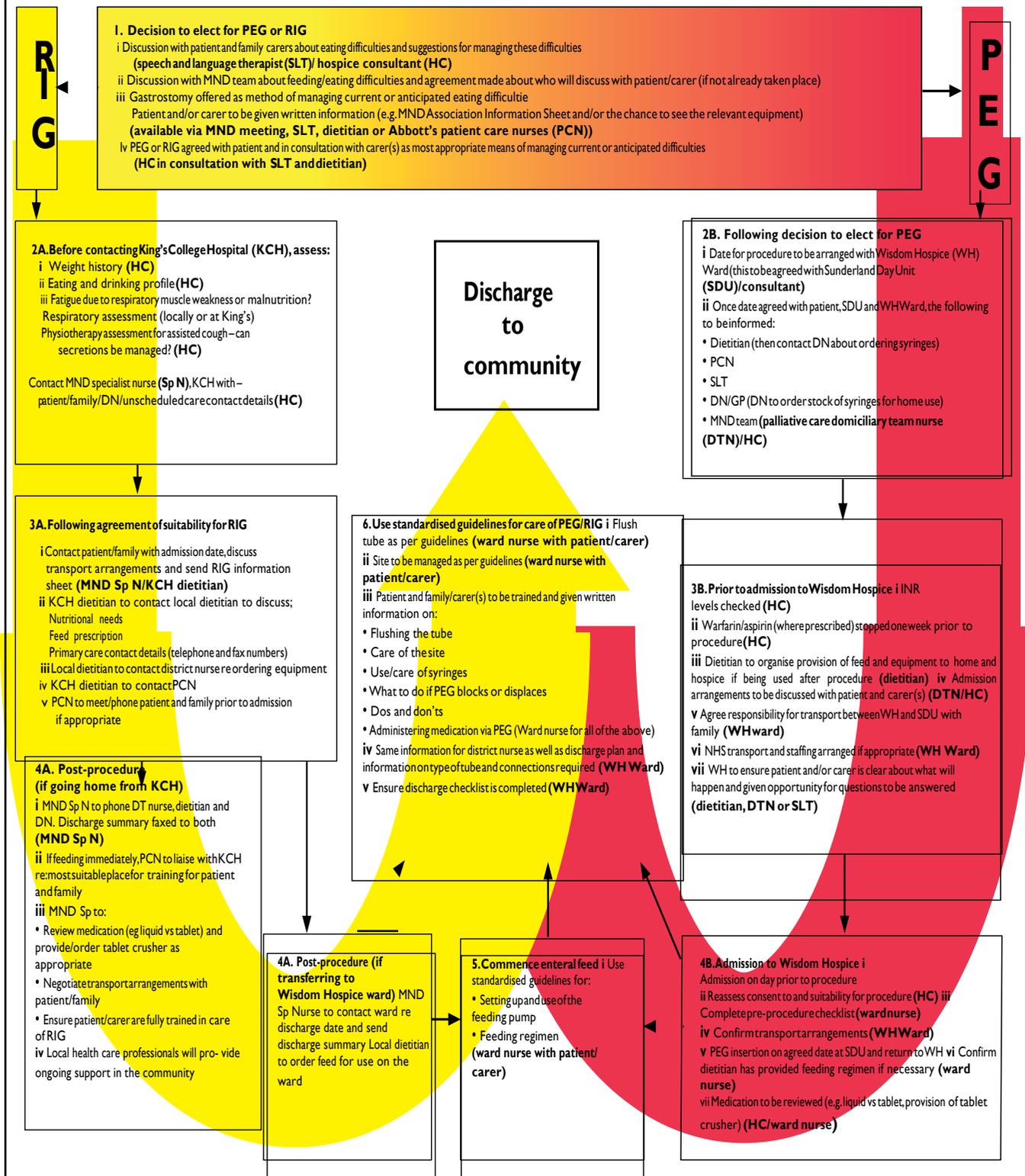


Figure 1. Gastrostomy insertion pathway



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